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A cross-sectional survey of healthcare professionals to determine what they believe constitutes 'specialist' care for teenage and young adult patients with cancer

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ABSTRACT

Objectives: To examine the attitudes of UK healthcare professionals towards what they believe constitutes specialist care for teenage and young adult (TYA) patients with cancer, to determine which factors they considered to be the most important components of specialist TYA care, and whether opinion varied between clinical specialties and reflected the drivers for care improvements within National Health Service (NHS) policy.

Design and methods: The study utilised a cross-sectional survey, using Likert scales, to assess attitudes towards specialist care. Responses were grouped using model-based clustering methods implemented in LatentGold 4.5.

Setting: Participants from 98 NHS trusts in the UK were invited to participate in the study.

Participants: 691 healthcare professionals involved in the management of TYA patients were approached; of these, 338 responded.

Results: 338 healthcare professionals responded (51.9% of those invited). Responses were grouped into three clusters according to the pattern of responses to the questions. One cluster rated age-appropriate care above all else, the second rated both age and site-appropriate care highly while the third assigned more importance to site-specific care. Overall, the psychosocial and supportive aspects of care were rated highest while statements relating to factors known to be important (access to clinical trials, treatment at a high volume centre and specialist diagnostics) were not rated as highly as expected.

Conclusions: Attitudes varied widely between professionals treating TYA patients with cancer as to what constitutes key aspects of specialist care. Further work is needed to quantify the extent to which this influences practice.

INTRODUCTION

The incidence of cancer in teenagers and young adults (TYA) is rare compared with that in older adults.¹ In recent years, only

ARTICLE SUMMARY

Article focus

- This study aimed to examine the difference in attitudes towards specialist care for teenage and young adult (TYA) patients with cancer among those involved in their care in an attempt to quantify the variation.

Key messages

- A wide range of attitudes towards specialist care is seen in those involved in the care of TYA patients with cancer.
- Three distinct groups of opinion exist, with each favouring a different aspect of care: age specific, cancer site specific or a combination of both.

Strengths and limitations of this study

- This is the first study of its kind to examine attitudes towards specialist care for TYA patients with cancer, and responses were received from a wide range of professionals with varying degrees of contact with TYA patients.
- Random sampling may have introduced bias, which is unavoidable using this methodology; however, results suggest that this was not a significant problem in this study.
- Further work would allow for responses from a wider study population and more in-depth examination of areas of disagreement.

around 2000 cases have been diagnosed annually in patients aged between 15 and 24;^{1 2} thus, its optimal management poses a major challenge to healthcare providers.

Challenges include not only the wide spectrum of cancers experienced by this age group but also the host and disease biology of these tumours, which can differ from that seen in both children and adults.^{3–6} Likewise, individuals in this age group also have very different psychosocial needs to

either adults or children.^{7–9} The optimal setting to meet these biological and psychosocial needs is, therefore, not ideally managed by adult or children's cancer teams, but by a TYA-specialist team drawing expertise from both professional groups. The widely varying spectrum of cancers affecting this age group and their unusual position in terms of age-focused services has led many to argue in favour of specialist care.^{10–12} However, owing to the different age-specific and cancer-specific care needs involved, there is, as yet, no consensus on what constitutes such 'specialist' care.^{10–12–14}

Access to tumour-specialist multidisciplinary teams (MDTs), age-specialist MDTs and specialist diagnostic services, clinical trials and specialist supportive services have all been cited as crucial to optimal outcomes in tumour site-specific guidelines (National Institute for Health and Clinical Excellence cancer service guidelines¹¹). Other guidelines place more emphasis on the importance of age-specific services and the availability of psychosocial and late effects supportive care.¹⁵ Principal treatment centres (PTC) have been advocated where patients have access to specialist environments of care, as were appropriately trained professionals from both site-specific and age-specific teams working together closely. A larger degree of specialisation than other cancer units has been supported. Three different types of PTC exist with three different foci: TYA-specific (teenage cancer trust (TCT) unit),¹⁶ paediatric (Children's Cancer and Leukaemia Group (CCLG) unit)¹⁷ and cancer site-specific units.¹⁸ In some cases, a single centre may include all three types of specialist units.

There is known variation in where, how and by whom TYA patients with cancer are treated.^{19–20} What is not fully understood is whether this is due to the availability of services (both geographically and age wise), patient's choice or physician's decision. Understanding the attitudes of those who treat this age range is vital to gaining a clearer insight into the key components of care of this age group, and therefore determining to what extent varying attitudes may be influencing the variation in treatment.

Policy states that treatment at a PTC is a key part of the cancer treatment pathway, as is access to clinical trials, MDT follow-up, age and cancer site appropriate care.¹¹ The latter has not been examined in detail, and therefore this study aimed to examine the variation in attitudes towards specialist care for TYA patients among those involved in the treatment of this group, and to determine whether opinion mirrored policy. It also aimed to quantify any variation noted and to establish whether this was associated with specific characteristics of the respondents such as job title, type of centre and caseload.

PARTICIPANTS AND METHODS

Sample selection

A list of healthcare professionals from National Health Service (NHS) trusts across the UK (England, Scotland,

Wales and Northern Ireland) involved in the treatment of TYA patients were identified using NHS trust websites. Individuals, including doctors, nurses and other health professionals, such as radiographers and physiotherapists, with a specialty which involved the care of patients with cancer and whose contact details were available on the NHS trust website, were included. Email addresses were freely available for 98 trusts in the UK at the time of this study. Each individual was contacted by email during June 2009 and asked to complete the questionnaire and to forward it to others to whom it might have been of interest. Non-responders received two follow-up emails between December 2009 and February 2010.

Survey development and study protocol

The survey consisted of a list of statements (table 1) about factors that had been identified in the medical literature as being potentially important features of specialist TYA cancer care.^{10–12–19–21–25} The statements encompassed both age-appropriate and site-specific features of care alongside more general aspects of cancer services. Respondents were asked to rate these 27 statements using a Likert scale (1—low importance to 5—high importance). Questions regarding the age range that respondents deemed appropriate for TYA patients, respondent's specialty and affiliation with a TCT unit were also included.

Statistical analysis

Descriptive statistics were used to describe demographics of respondents. Mann-Whitney tests were used to examine the difference between demographic information and the responses on the 5-point Likert scale.

Missing information was recorded as such in the analysis, as the proportion of respondents who left each question blank was considered an interesting outcome in its own right.

Model-based latent cluster analysis was used to establish underlying characteristics and relationships that could be used to group data into natural/latent classes. The Bayesian information criterion score was used to determine the number of latent classes which provided the best fit to the respondents' data. The analysis was performed using Stata 11 and Latent Gold 4.5.²⁷

RESULTS

Six hundred and ninety-one healthcare professionals from 98 NHS trusts were asked to complete the questionnaire and 338 (51.9%) responded. The characteristics of the respondents are detailed in table 2. In all, 253 (74.9%) were from England, 21 (6.2%) from Northern Ireland, 30 (8.9%) from Scotland and 34 (10.1%) from Wales. One hundred and ninety (56.2%) reported that they were affiliated with a teenage cancer unit and 208 (61.5%) were linked to a CCLG unit. The majority of respondents belonged to a medical rather than a surgical specialism (78.4% vs 21.6%, respectively). Over half

Table 1 Responses

Rank	Q	4 or higher		3		2 or lower		Missing		Question
		n	%	n	%	n	%	n	%	
1	16	314	92.9	10	3.0	8	2.4	6	1.8	Psychological and psychosocial support from those specialising in the care of teenagers and young adults.
2	14	314	92.9	11	3.3	8	2.4	5	1.5	Contact with a nurse specialising in the care of teenagers and young adults.
3	13	303	89.6	18	5.3	13	3.8	4	1.2	Treatment in an age-appropriate environment.
4	1	289	85.5	32	9.5	13	3.8	4	1.2	Treatment by a site-specific surgical or medical team.
5	12	286	84.6	34	10.1	13	3.8	5	1.5	Access to age-appropriate clinical trials.
6	21	285	84.3	32	9.5	18	5.3	3	0.9	Contact with peers who have undergone or are undergoing similar treatments or who have been diagnosed with the same illness.
7	6	285	84.3	38	11.2	10	3.0	5	1.5	Regular follow-up by a site-specific MDT.
8	5	285	84.3	40	11.8	6	1.8	7	2.1	Contact with a site-specific clinical nurse specialist or Macmillan nurse.
9	3	284	84.0	39	11.5	12	3.6	3	0.9	Access to site-specific clinical trials.
10	2	282	83.4	39	11.5	13	3.8	4	1.2	Diagnostics and staging by site-specialist clinical teams (radiology, pathology, etc)
11	10	256	75.7	44	13.0	34	10.1	4	1.2	Treatment by a medical or surgical team who specialise in the treatment and care of teenagers and young adults.
12	15	236	69.8	57	16.9	39	11.5	6	1.8	Regular follow-up by an age-specific MDT.
13	19	230	68.0	74	21.9	27	8.0	7	2.1	Treatment at a high volume cancer centre.
14	11	195	57.7	86	25.4	52	15.4	5	1.5	Diagnostics and staging by clinical teams specialising in the care of teenagers and young adults (radiology, pathology, etc).
15	7	194	57.4	10	3.0	6	1.8	128	37.9	Psychological and psychosocial support from those specialising in the care of persons with cancer.
16	26	192	56.8	10	3.0	3	0.9	133	39.3	Access to fertility specialists and advice on reproductive issues.
17	17	188	55.6	12	3.6	5	1.5	133	39.3	Access to age-appropriate palliative care if needed.
18	24	186	55.0	16	4.7	4	1.2	132	39.1	Support for family friends and partners of the patient.
19	18	184	54.4	15	4.4	7	2.1	132	39.1	Access to age-appropriate end of treatment care and support and information on late effects of treatment.
20	23	183	54.1	18	5.3	5	1.5	132	39.1	Educational and employment support during and after treatment.
21	27	179	53.0	17	5.0	9	2.7	133	39.3	Ability to stay in contact with peers when in hospital, Facebook, email text messages, etc
22	9	168	49.7	28	8.3	13	3.8	129	38.2	Access to site-specific end of treatment care and support and information on late effects of treatment.
23	25	167	49.4	30	8.9	10	3.0	131	38.8	Treatment by the same team throughout.
24	8	160	47.3	30	8.9	17	5.0	131	38.8	Access to site-specific palliative care if needed.
25	22	141	41.7	43	12.7	22	6.5	132	39.1	Outpatient appointments held in an age-appropriate environment.
26	20	129	38.2	116	34.3	86	25.4	7	2.1	Treatment at a hospital in close proximity to a patient's home address.
27	4	114	33.7	90	26.6	128	37.9	6	1.8	Inpatient treatment on a site-specific ward (eg, breast).

MDT, multidisciplinary team.

of all those who responded (55.7%) reported that less than 10% of their annual workload comprised TYA patients and only 35 respondents (16.8%) reported seeing more than 20 TYA oncology patients annually. In total, 129 respondents (38.2%) failed to report the number of TYA patients treated annually; however, only 2 (0.6%) failed to report the proportion of their total caseload which consisted of TYA patients. The most frequently suggested lower age range for a TYA service was 13 (52.7%, range 11–19 years of age) and the most

commonly (modal) recommended upper age limit was 25 (25.7%, range 16–40 years of age).

Many respondents also recorded that the patient range should not be restricted by age but by the diagnostic group and emotional maturity of the patient. The latent class model identified three clusters of respondents with specific attitudes concerning specialist care (figure 1).

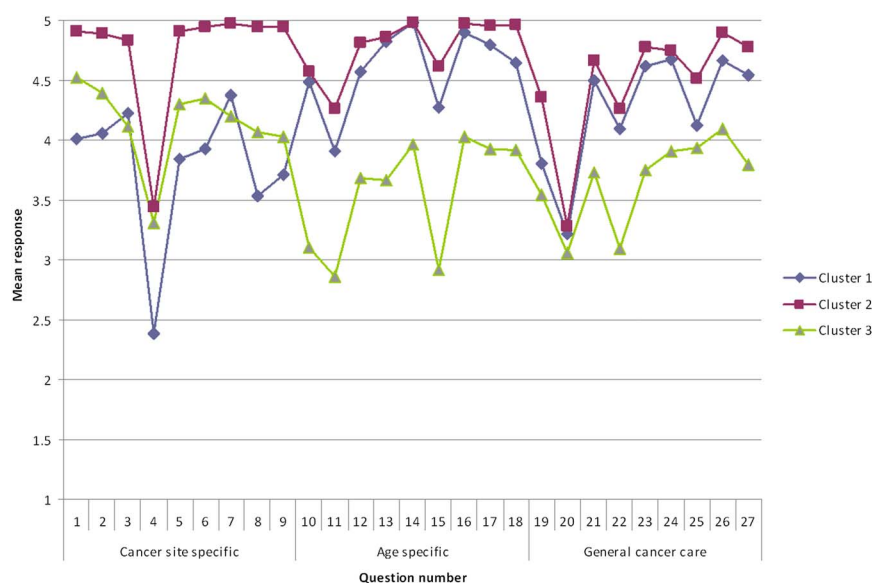
Cluster 3 rated the treatment by a site-specific team higher than an age-specialist team, but did not rate any

Table 2 Characteristics of respondents

	Cluster 1		Cluster 2		Cluster 3		Total
	n	%	n	%	n	%	
Country							
England	100	34.0	107	36.4	87	29.6	294
Scotland	6	40.0	5	33.3	4	26.7	15
Wales	5	27.8	9	50.0	4	22.2	18
Northern Ireland	3	27.3	3	27.3	5	45.5	11
Self-reported job title							
Doctor	99	42.3	69	29.5	66	28.2	234
Nurse	9	14.1	36	56.3	19	29.7	64
Radiographer	1	10.0	1	10.0	8	80.0	10
Management	1	14.3	3	42.9	3	42.9	7
Social worker	0	0.0	3	60.0	2	40.0	5
Other	4	23.5	11	64.7	2	11.8	17
Unknown	0	0.0	1	100.0	0	0.0	1
Specialism							
Medical	92	33.9	103	38.0	76	28.0	271
Surgical	22	32.8	21	31.3	24	35.8	67
Area of expertise							
Oncology	38	26.8	57	40.1	47	33.1	142
Haematology	27	60.0	13	28.9	5	11.1	45
Paediatrics	10	55.6	1	5.6	7	38.9	18
Gynaecology	2	11.1	10	55.6	6	33.3	18
ENT	8	50.0	6	37.5	2	12.5	16
Palliative medicine	4	26.7	10	66.7	1	6.7	15
General surgery	3	21.4	4	28.6	7	50.0	14
Radiology	0	0.0	3	30.0	7	70.0	10
Other surgical specialty	18	35.0	2	15.0	15	45.0	35
Other non-surgical specialty	6	42.9	5	35.7	4	21.4	15
Other	6	42.9	14	35.7	6	21.4	26
Type of specialist interest							
Age	9	18.4	15	30.6	25	51.0	49
Site	79	39.3	72	35.8	50	24.9	201
Both	26	29.9	36	41.4	25	28.7	87
Unknown	0	0.0	1	100.0	0	0.0	1
Teenage cancer unit							
Yes	58	30.5	83	43.7	49	25.8	190
No	56	37.8	41	27.7	51	34.5	148
CCLG unit							
Yes	70	33.7	70	33.7	68	32.7	208
No	44	33.8	54	41.5	32	24.6	130
Number of TYA patients seen annually							
0–5	43	44.3	28	28.9	26	26.8	97
6–10	25	52.1	10	20.8	13	27.1	48
11–15	3	16.7	8	44.4	7	38.9	18
16–20	3	27.3	5	45.5	3	27.3	11
21+	3	8.6	17	48.6	15	42.9	35
Unknown	37	28.7	56	43.4	36	27.9	129
Proportion of overall caseload consisting of TYA							
Less than 10%	87	46.3	47	25.0	54	28.7	188
10–20%	14	26.9	23	44.2	15	28.8	52
20–30%	6	19.4	11	35.5	14	45.2	31
30–40%	4	26.7	9	60.0	2	13.3	15
Greater than 40%	3	6.0	32	64.0	15	30.0	50
Unknown	0	0.0	2	100.0	0	0.0	2
Total	114	33.7	124	36.7	100	29.6	338

CCLG, Children's Cancer and Leukaemia Group; TYA, teenage and young adult.

Figure 1 Cluster analysis of responses to the survey.



of the statements as highly as clusters 1 and 2, indicating that individuals in cluster 3 answered more questions as being of neither high nor low importance.

Cluster 1 rated age-appropriate treatment very highly in all areas while cluster 2 rated most points highly and did not favour either age-specialist or site-specialist care. Overall, it appeared that clusters should be grouped as follows:

Cluster 1—Age-specific preference

Cluster 2—Combined age-specific and site-specific preference

Cluster 3—Cancer site-specific preference

The variation in responses between the three clusters was statistically significant for all questions ($p \leq 0.01$), with the exception of question 20 ($p = 0.61$).

On further examination of the self-reported interests of the respondents (table 2), the distribution of those affiliated with a TCT or a CCLG unit was found to be even across the three clusters. The majority of individuals in cluster 3, which favoured site-specialist treatment, had a site-specific interest (eg, colorectal or breast surgery), and contained a greater proportion of those with a surgical specialty than any other cluster. Persons within cluster 2 treated the highest number of TYA cases annually, while cluster 1 treated the lowest, with 68 respondents reporting seeing fewer than 11 cases annually.

When the questions were ranked in order of importance, the three questions ranked mostly highly were (table 1): (1) psychological and psychosocial support from those specialising in the care of TYA (314 respondents (92.9%) marked as a 4 or higher); (2) contact with a nurse specialising in the care of TYA (314 respondents (92.9%) marked as a 4 or higher); and (3) treatment in an age-appropriate environment (303 respondents (89.6%) marked as a 4 or higher). The three statements ranked the lowest were: (1) inpatient treatment on a site-specific ward (eg, breast) (128 respondents (37.9%) marked as a 2 or lower); (2) treatment at a hospital in close proximity to a patient's home address

(86 respondents (25.4%) marked as a 2 or lower); and (3) diagnostics and staging by clinical teams specialising in the care of teenagers and young adults (radiology, pathology, etc) (52 respondents (15.4% marked as a 2 or lower). The three statements which ranked the lowest also had the greatest number of indifferent responses (scored 3 on the Likert scale). Aspects of care often discussed as being key aspects of specialist care for TYA patients by patients themselves⁸ ranked relatively low on the scale. Access to clinical trials, particularly site-specific, ranked around the middle of the table of ordered responses (ranked ninth most important). Treatment at a high volume cancer centre was also ranked of relatively low importance with only 230 respondents (68.0%) scoring this 4 or higher and 74 (21.9%) recording it as neither of high nor low importance.

Statements ranked 15th to 25th overall were unanswered in over 35% of cases. These questions related mainly to psychosocial support, palliative care and long-term follow-up. This was vastly different to the number of missing answers for other questions (range 3–7 missing answers). The focus of these questions may have led a greater proportion of respondents to leave them unanswered; previous studies have shown a patchy and irregular referral to supportive services, suggesting a greater degree of indifference than shown in the other areas addressed in the study.^{27 28}

DISCUSSION

This study demonstrates widely varying opinions as to what is important in the care of TYA patients with cancer. Attitudes were divided into three categories: those who advocated age-appropriate care, those who preferred tumour-site-specialist care and those who promoted a combination of both age-specialist and site-specialist care. The characteristics of individuals in these three clusters were different, with specialism, caseload

and involvement with either a TYA or a CCLG unit varying between groups. Aspects of care which are frequently the focus of policy, such as access to a high volume cancer centre and access to clinical trials, were assigned lower importance than expected, as were all aspects related to end of life care.

Current policy states that all patients in the TYA age range should at least be offered the opportunity to be treated at a PTC and to receive specialist care.¹¹ This study reflects the varying attitudes towards specialist care for this age group and illustrates the difficulties in fully implementing policy in relation to the differing degrees of importance associated to it. Where the rhetoric is not believed by all those involved in the diagnostic, treatment and support pathway for this patient group, and as long as flexibility remains, specialist TYA cancer care, as it is currently defined, will not be implemented consistently.

As a relatively young area of cancer treatment with a multitude of diagnoses and treatment options, the pathways and protocols for TYA cancer care are known to vary. Not all TYA patients are treated at TYA specialist units; in some cases, this may be due to patient choice, while in others it could be due to a lack of appropriate referral to the units. This variation alongside the disagreement as to what constitutes the key aspects of care for TYA with cancer may demonstrate the need for multidisciplinary involvement in order to ensure that patients receive the best of all elements of care. All the respondents to this survey were actively involved in the treatment of TYA patients but have extremely divergent views as to what constitutes 'specialist' care; this may go some way to explain why there is variation in how and where many TYA patients are treated. A preference towards one type of care, age or site over another may lead to an increased likelihood of favouring that care setting and a decreased chance of utilisation of other available services.

Wider implications

This study did not ask respondents whether their attitudes to specialist care would influence their practice but instead focused on the importance assigned to individual aspects of care in the wider picture. In an area such as TYA cancer care, where policy implementation is known to vary by geography and patient demographics, there is a degree of flexibility in terms of patient pathways. The attitude of professionals involved at each stage of the patient's journey is likely to at least partly influence the choices made. Unfortunately, in this case it was not possible to assess the extent to which the influence of clinicians varies at different points in the diagnostic and treatment pathways. Understanding the range and strength of opinions is vital before attempting to determine to what extent it influences practice. Policy states that patients should be reviewed by both a TYA and a site-specific MDT, emphasising that these should not be considered mutually exclusive.

Limitations

This is the first study to examine attitudes towards specialist cancer care in this age group. The method of recruitment to the study (random sampling) may have introduced bias, with those treating a high volume of TYA patients, and those belonging to a medical specialty, being more likely to reply than others. It is not possible to address this issue in a random sample study of this nature; however, the self-reported caseload figures and distribution of medical staff across the clusters (table 2) suggest that this has not been a significant problem. A similar issue was also identified regarding the proportion of respondents who identified an affiliation with a CCLG unit, which may have been due to the relatively large number of centres in comparison to TCT centres at the time of the study. Respondents were asked to identify any association between themselves and a specialist unit, including occasional contact, so this does not necessarily mean that this will have resulted in bias in the results.

A large proportion of questions regarding psychosocial support were unanswered; the reasoning behind this is not understood and, owing to the nature of the survey (Likert scale), it was not possible to investigate this in more detail. Additional work could be performed to address this using a more detailed survey assessing these aspects of care.

This study was undertaken in 2009, 5 years after the release of the Improving Outcomes Guidelines, and therefore will be reflective of attitudes to specialist care after the service redesign. Attitudes are likely to have altered since the survey was undertaken; however, the greatest degree of change is likely to have taken place relatively quickly after the publication of the guidance. In order to quantify any further changes in opinion, the study could be performed again, using a similar cohort.

Further work is also now needed to assess to what extent the attitudes of those treating TYA patients with cancer influence their practice, including an analysis of the attitudes of those referring patients for treatment and an assessment of the degree of variation between NHS trusts and cancer networks. In order to assess the different influences which may be affecting the variation in attitudes, such as proximity to a specialist centre and duration of association with a PTC, greater detail regarding the location and affiliation of the respondents would be sought and analysed. Additional work to determine any association between attitude and patient decision-making and variation in attitudes and patient outcomes would also add more detail to the understanding of a complex area.

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Contributors RJB designed data collection tools, monitored data collection for the whole trial, wrote the statistical analysis plan, cleaned and analysed the data, and drafted and revised the paper. She is the guarantor. EJAM aided in the statistical analysis, drafted and revised the paper. RMW designed data collection tools, aided in statistical analysis and revised the draft paper. DPS aided in the design of the study, drafted and revised the paper. IL aided in the design of the study, drafted and revised the paper. SM aided in the design of the study, drafted and revised the paper. RGF drafted and revised the paper. All authors read and approved the final manuscript.

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Competing interests None.

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